



*• a grassroots advocacy effort •*

**Statement of**

**Frances M. Visco, Vice President  
National Breast Cancer Coalition**

**in support of the  
Patients' Bill of Rights Act of 1998**

**May 13, 1998**

---

On behalf of the 450 organizations and tens of thousands of individuals who are members of the National Breast Cancer Coalition (NBCC), I applaud Sens. Daschle and Kennedy and Reps. Gephardt and Dingell and the additional Congressional supporters of the "Patients' Bill of Rights Act of 1998." The NBCC is committed to working to ensure access to effective, quality health care for all Americans. We support this legislation which is an important step toward that goal.

The NBCC is dedicated to the eradication of breast cancer through action and advocacy: it seeks to increase the influence of breast cancer survivors and other activists over research, clinical trials, and public policy and to ensure access to quality health care for all women. NBCC recognizes that the evolving health care system affords us the opportunity to define and focus on true quality of care for women and their families. We cannot afford to let this opportunity pass.

The NBCC believes that breast cancer patients have fundamental rights, including: the right to receive accurate information about their health plans; access to the right providers; involvement in treatment decisions that are based on good science; confidentiality of their health information; and coverage for routine health care costs associated with participation in clinical trials.

One of the NBCC's most pressing concerns is that health insurance and managed care plans are erecting barriers to good science by increasingly refusing reimbursement for routine patient costs when breast cancer patients participate in approved clinical trials. This practice is preventing us from finding desperately needed scientific answers about breast cancer and severely affects the treatment breast cancer patients receive. Only three percent of adult cancer patients are enrolled in clinical trials -- insurance reimbursement is often a major obstacle to clinical trial participation. In fact, one of our NBCC members who participated in an NCI clinical trial five years ago, only recently resolved her legal battles with her insurance company over coverage of the costs associated with the NCI trial. The Patients' Bill of Rights Act is an important first step in ensuring third party coverage for the routine patient costs incurred within a clinical trial.

The NBCC is prepared to work with the Congress, and will mobilize our nation-wide network of advocates to ensure that meaningful legislation like the Patients' Bill of Rights Act is enacted into law. We offer thanks to all of the leaders gathered here today for their work to ensure that breast cancer patients and all American women and families receive quality health care.

###